The Partnership to Reduce Cancer in Rhode Island

CURRENT TRENDS FUTURE DIRECTIONS

ANNUAL REPORT, JUNE 2009

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RHODE ISLAND BEHAVIORAL RISK FACTOR SURVEILLANCE SYSTEM DATA FOR 2007 ARE PROVIDED BY THE CENTER FOR HEALTH DATA AND ANALYSIS, RHODE ISLAND DEPARTMENT OF HEALTH, AND SUPPORTED IN PART BY THE NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION, CENTERS FOR DISEASE CONTROL AND PREVENTION COOPERATIVE AGREEMENT U58/CCU122791 (2003–2007).


A MAIN PRIORITY OF THE PARTNERSHIP IS TO ADDRESS ISSUES OF HEALTH DISPARITIES AND TO INCLUDE A DIVERSE REPRESENTATION OF THE POPULATION IN THE COLLABORATIVE PROCESS.

THE MISSION OF THE PARTNERSHIP TO REDUCE CANCER IN RHODE ISLAND

The mission of *The Partnership to Reduce Cancer in Rhode Island* is to reduce the burden of cancer for the residents of Rhode Island by working collaboratively to:

» Educate and advocate on cancer issues;

» Ensure Rhode Islanders have access to care, prevention, early detection, treatment, and support services; and

» Promote research.

OUR STATE HAS A PLAN TO REDUCE CANCER IN RHODE ISLAND.
WE'RE WORKING TOGETHER TO MAKE THAT HAPPEN.

COLLABORATION YIELDS RESULTS

The Partnership to Reduce Cancer in Rhode Island is a broad-based coalition of partners who have come together to provide input in planning and implementation of programs and services around comprehensive cancer control. Comprehensive cancer control is a collaborative process through which a community and its partners organize to promote cancer prevention, improve cancer detection, increase access to health and social services, and reduce the burden of cancer.

The work of The Partnership is focused on implementation of the *Rhode Island Comprehensive Cancer Control State Plan,* published in June 2007 in collaboration with the Rhode Island Department of Health Comprehensive Cancer Control Program. The goals and objectives of this plan guide The Partnership's efforts in reducing the burden of cancer in the state. Following extensive evaluation, a new five-year state plan will be presented in June 2012.

GOALS OF THE PARTNERSHIP

Reduce cancer risk through changes in behavior, policies, and environment that promote healthy lifestyles.

Increase proven, science-based cancer screening rates among all segments of the population in Rhode Island.

Ensure access to cancer care for all residents of Rhode Island.

Improve the quality of cancer treatment provided in Rhode Island.

Enhance the treatment experience for cancer patients.

Reduce workforce gaps and ensure an adequate supply of diverse and highly-trained professionals in all aspects of cancer care and control.

Increase awareness, access, and participation in cancer clinical trials by Rhode Island residents.

Improve access to palliative care for all Rhode Island patients seeking end-of-life care due to cancer.

Promote the well being and quality of life of Rhode Islanders who are living with, through, and beyond cancer.

Assure the use of timely, complete, and accurate cancer surveillance data in the planning, management, and evaluation of cancer control programs.

THE BURDEN OF CANCER IN RHODE ISLAND

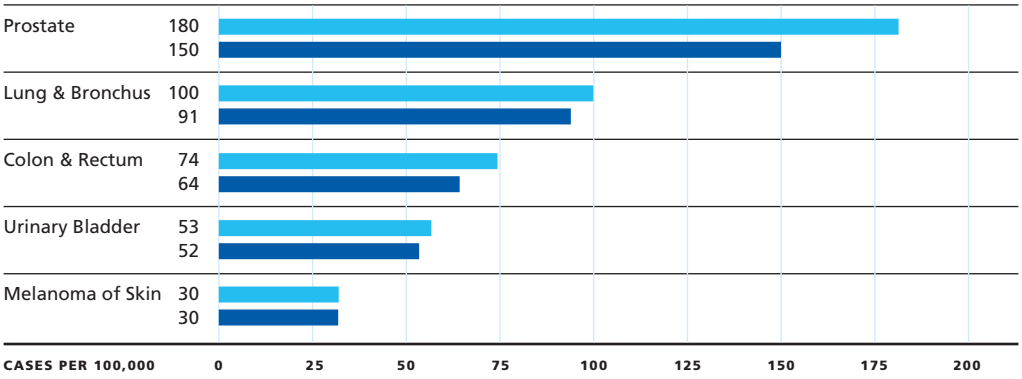
More than 43,000 Rhode Island residents—4% of the population—are currently living with cancer. Approximately 6,120 new cases of cancer are diagnosed each year.

The five most common newly diagnosed cancers in Rhode Island are cancers of the prostate, lung-bronchus, female breast, colon-rectum, and urinary bladder. Together, these cancers represent about half of all cancers diagnosed.

Among Rhode Island men, the incidence of the three major cancers (prostate, lung-bronchus, and colon-rectum) has declined recently (Figure 1). Among Rhode Island women, the incidence of two major cancers (breast and colon-rectum) has declined recently (Figure 2).

FIGURE 1. LEADING MALE CANCER SITES

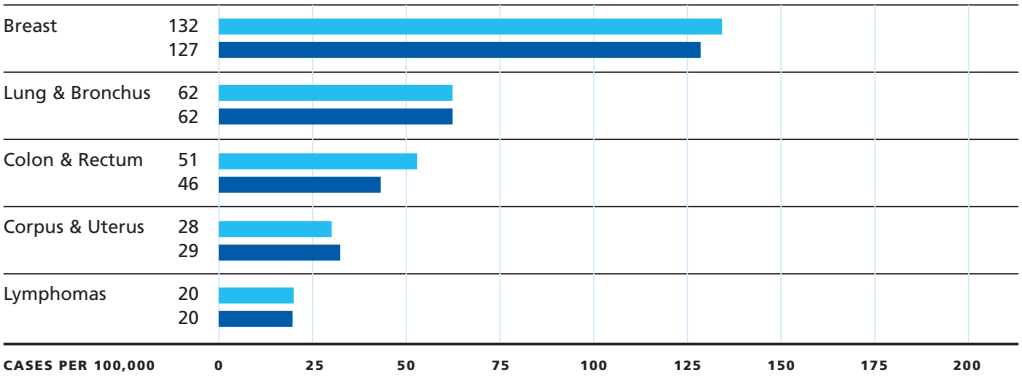
CANCER INCIDENCE RATES,* MALES, RI, 1999–2003 AND 2002–2006



*Rates are age-adjusted to the 2000 US standard population.
Source: Rhode Island Cancer Registry.

FIGURE 2. LEADING FEMALE CANCER SITES

CANCER INCIDENCE RATES,* FEMALES, RI, 1999–2003 AND 2002–2006



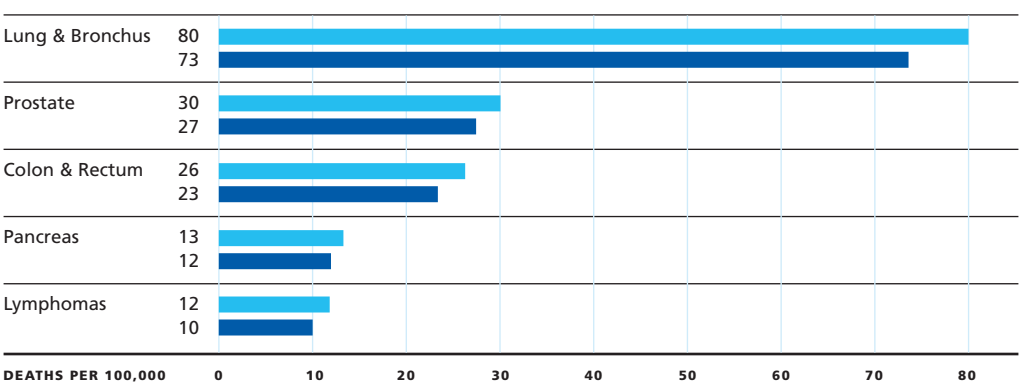
*Rates are age-adjusted to the 2000 US standard population.
Source: Rhode Island Cancer Registry.

CANCER MORTALITY IN RHODE ISLAND

Approximately 2,310 Rhode Island residents will die of cancer this year. Four of the five most commonly diagnosed cancers (lung-bronchus, colon-rectum, female breast, and prostate) account for about half of all cancer deaths. Among men, mortality from leading cancers has declined recently (Figure 3). Among women, mortality from cancers of the breast and colon-rectum has declined (Figure 4).

FIGURE 3. LEADING MALE CANCER DEATHS

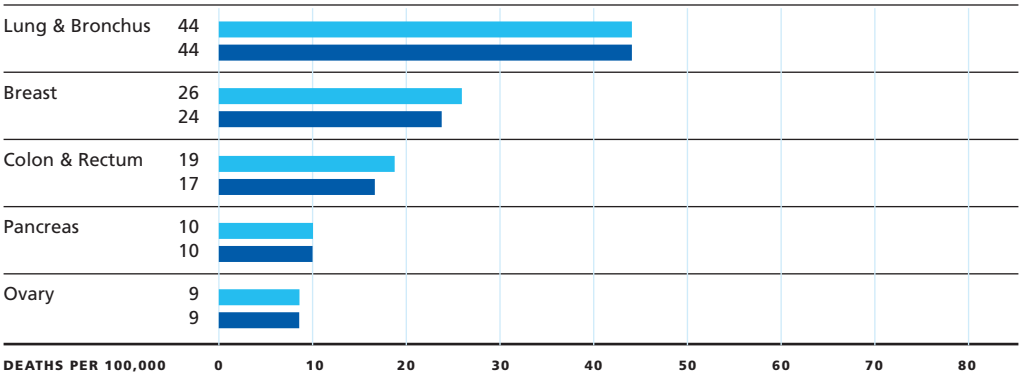
CANCER MORTALITY RATES,* MALES, RI, 1998–2002 AND 2001–2005



*Rates are age-adjusted to the 2000 US standard population.
Source: National Center for Health Statistics

FIGURE 4. LEADING FEMALE CANCER DEATHS

CANCER MORTALITY RATES,* FEMALES, RI, 1998–2002 AND 2001–2005



*Rates are age-adjusted to the 2000 US standard population.
Source: National Center for Health Statistics

DISPARITIES

Cancer disproportionally affects different population groups in Rhode Island. Most strikingly, men have both higher incidence and mortality rates than women (Figures 1–4 on previous pages).

In terms of race, white men in Rhode Island have a higher incidence rate of all cancers combined (Figure 6), yet African American men have a higher mortality rate (Figure 7). White women in Rhode Island have slightly higher incidence and mortality rates than African American women (Figures 6 & 7).

In terms of ethnicity, recent observations reveal similar all-cancer incidence rates for Hispanics and non-Hispanics in Rhode Island (Figure 8). However, Hispanics in Rhode Island have higher incidence rates compared to Hispanics nationally (Figure 8). In terms of mortality, Hispanics in Rhode Island, as well as in the nation as a whole, have lower mortality rates than non-Hispanics (Figure 9).

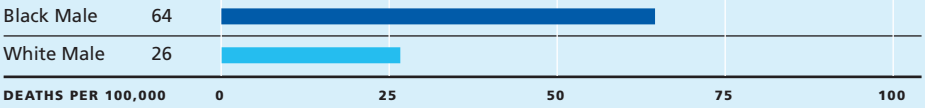
Cancer trends in Rhode Island do not mimic those nationally. Rhode Island has the highest overall incidence rate among the 50 states. Incidence rates are higher in Rhode Island for whites and Hispanics of both genders than national rates (Figure 8). However, incidence rates are lower in Rhode Island for both male and female African Americans than nationally (Figure 6).

Mortality in Rhode Island tells a different story. Mortality rates in Rhode Island are lower for Hispanics and African Americans of both genders, and are similar to national rates for male and female non-Hispanics and whites (Figures 7 & 9).

SPOTLIGHT ON PROSTATE CANCER AMONG AFRICAN AMERICANS

African Americans and whites in Rhode Island are notably different in terms of prostate cancer mortality. African American men have a much higher prostate cancer mortality rate than white men, 64 versus 26 deaths per 100,000 per year. Overall, research suggests that there are biological and social differences between African American and white men in terms of prostate cancer development and screening practices.

FIGURE 5. PROSTATE CANCER DEATHS BY RACE, MALES IN RHODE ISLAND, 2001–2005



Rates are age-adjusted to the 2000 US standard population.
Source: National Center for Health Statistics

CANCER COST

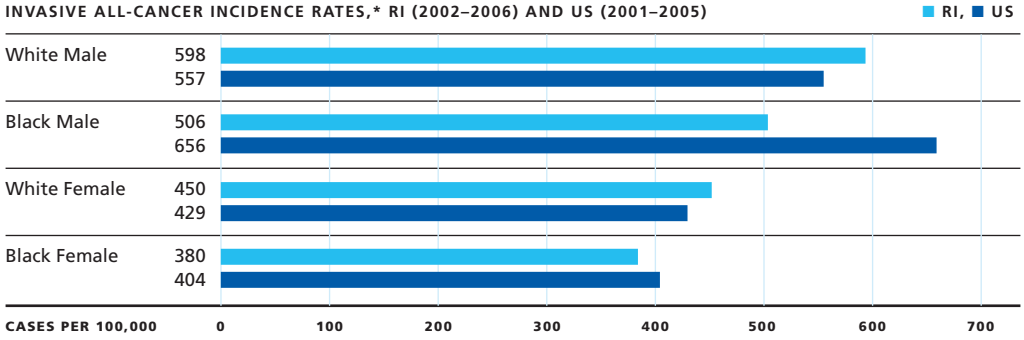
Cancer costs in Rhode Island, including both direct medical costs and productivity lost, are estimated to cost more than $750 million annually, placing a considerable burden on patients, families, and the healthcare system.

SURVIVORSHIP

More than 43,000 Rhode Island residents are cancer survivors (55% female, 45% male). Sixty-six percent of survivors are between the ages of 50 and 79.

FIGURE 6. CANCER INCIDENCE BY RACE AND GENDER

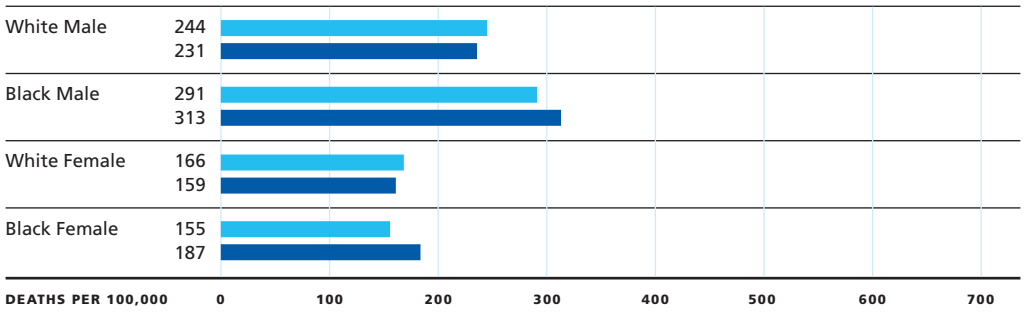
INVASIVE ALL-CANCER INCIDENCE RATES,* RI (2002–2006) AND US (2001–2005)



*Rates are age-adjusted to the 2000 US standard population.
Source: Rhode Island Cancer Registry; National Cancer Institute Surveillance Epidemiology and End Result (NCI/SEER) Program

FIGURE 7. CANCER MORTALITY BY RACE AND GENDER

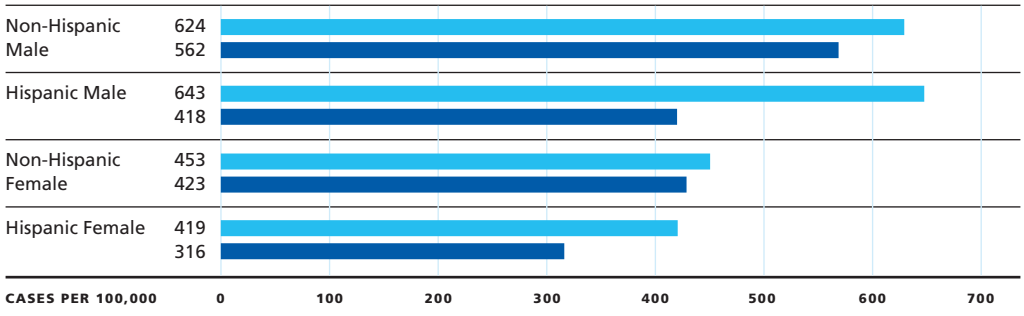
INVASIVE ALL-CANCER MORTALITY RATES,* RI AND US, 2001–2005



*Rates are age-adjusted to the 2000 US standard population.
Source: National Center for Health Statistics

FIGURE 8. CANCER INCIDENCE BY ETHNICITY AND GENDER

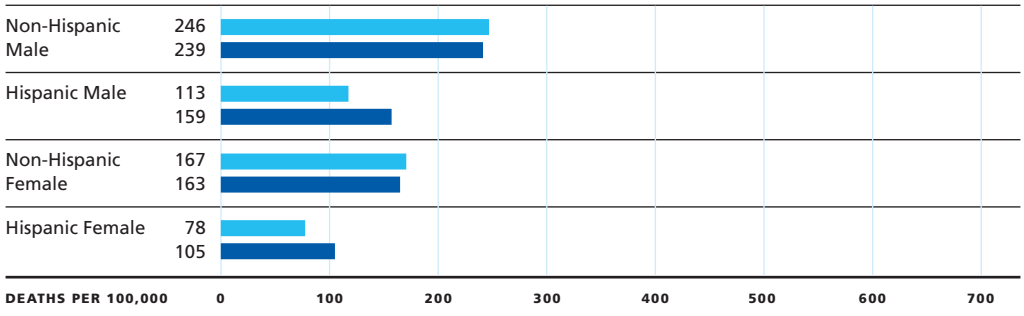
INVASIVE ALL-CANCER INCIDENCE RATES,* RI AND US, 2001–2005



*Rates are age-adjusted to the 2000 US standard population.
Source: Rhode Island Cancer Registry; National Cancer Institute Surveillance Epidemiology and End Result (NCI/SEER) Program

FIGURE 9. CANCER MORTALITY BY ETHNICITY AND GENDER

INVASIVE ALL-CANCER MORTALITY RATES,* RI AND US, 2001–2005



*Rates are age-adjusted to the 2000 US standard population.
Source: National Center for Health Statistics

FROM PUBLIC HEALTH PROFESSIONALS, HEALTH CARE PROVIDERS, AND BUSINESSMEN AND WOMEN, TO SURVIVORS AND INDIVIDUAL ADVOCATES, OUR MEMBERS ARE ALL DRIVEN TO REDUCE THE BURDEN OF CANCER IN RHODE ISLAND.

PARTNERSHIP WORKGROUPS

PUTTING VISION INTO ACTION

The Partnership has six workgroups whose members work collaboratively to reduce the burden of cancer in Rhode Island. Worksgroups include Prevention, Detection and Screening, Treatment, Survivorship, Palliative Care, and Surveillance and Evaluation.

Annually, workgroups identify key priorities and create strategies to address them. Throughout the year, workgroups meet monthly to implement programs and services, as well as continue to make strides towards policy change.

WORKGROUP

PREVENTION

CHAIR: SUSAN SHEPARDSON, CO-CHAIR: PAUL MADRAZO

The Prevention Workgroup focuses on lifestyle choices and environmental factors which profoundly affect cancer incidence and mortality. In 2008, the workgroup chose to support and improve the utilization of the Human Papillomavirus (HPV) vaccine, which has been proven to protect against 90% of the HPV types that cause cervical cancer, as well as many cancers of the head, neck, anus, and penis. The development of the HPV vaccine offers a tremendous opportunity to reduce the burden of cervical cancer across the state.

THE DEVELOPMENT OF THE HPV VACCINE OFFERS A TREMENDOUS OPPORTUNITY TO REDUCE THE BURDEN OF CERVICAL CANCER ACROSS THE STATE.

The workgroup's goals regarding HPV vaccination include: supporting the federal Advisory Committee on Immunization Practices (ACIP) recommendations, educating providers and members of the public about the importance of HPV vaccination in target populations, and enhancing data tracking to ensure the completion of the three-dose series. As a component of its education and advocacy work around HPV vaccination, the workgroup also plans to address skin cancer prevention within the same target populations.

WORKGROUP

DETECTION & SCREENING

CHAIR: CHRISTY DIBBLE, DO, CO-CHAIR: DAVID ROUSSEAU

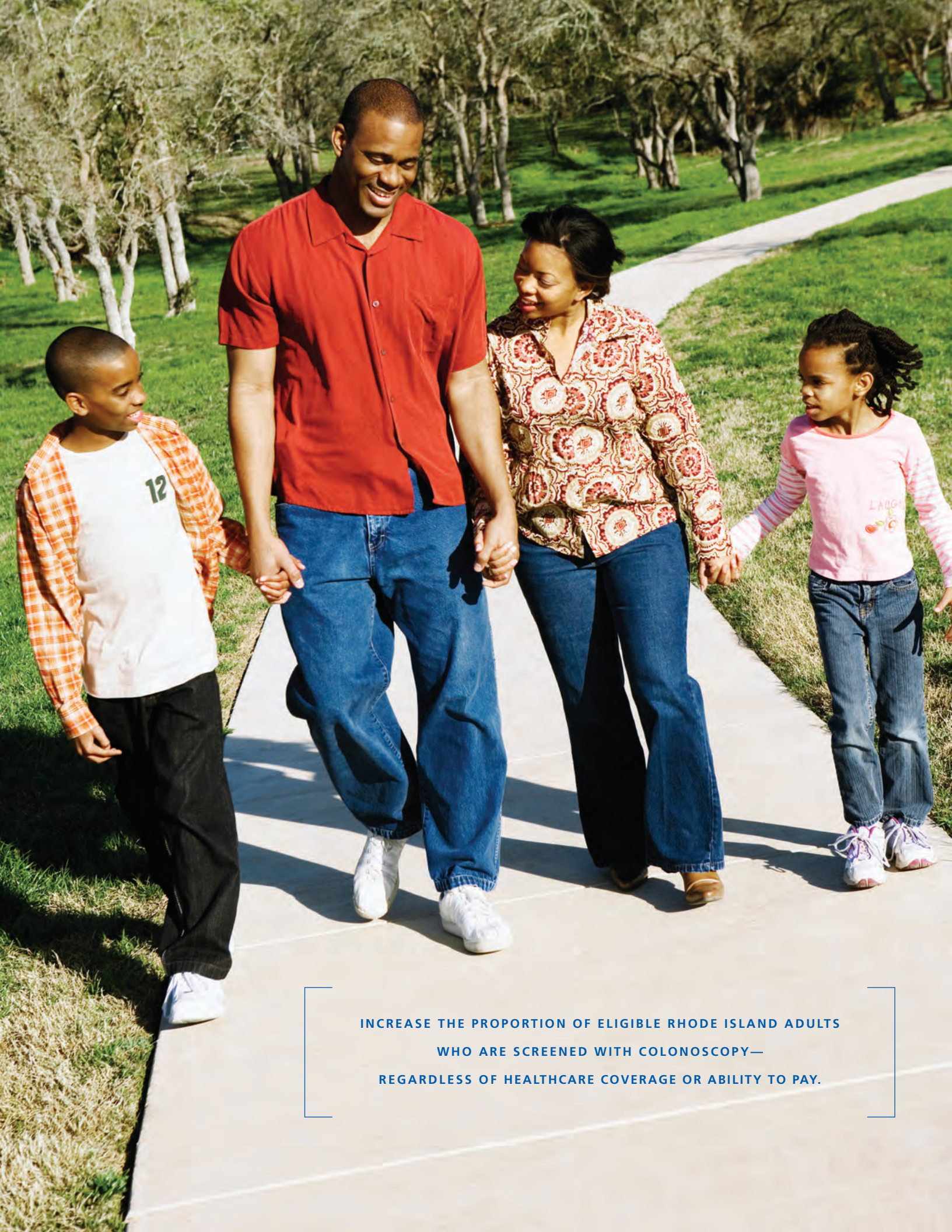
The Detection and Screening Workgroup is currently concerned with screening for colorectal cancer. Colorectal cancer is the second highest leader of cancer mortality in Rhode Island, and Rhode Island's rates are higher than the national average. The workgroup has chosen to focus on increasing the proportion of eligible Rhode Island adults who are screened with a colonoscopy—regardless of healthcare coverage status or ability to pay—based on the United States Preventive Services Task Force preference for mode of screening.

To increase rates of colonoscopy, the workgroup is looking at current education efforts related to colorectal cancer and the need for colonoscopy, with a special focus on low-income, uninsured populations and racial and ethnic minorities. Outreach strategies to promote colonoscopy include: onsite education at primary care practices; education and information at senior centers; and multilingual educational materials at various sites.

NUMBER AND PERCENTAGE OF RHODE ISLANDERS OLDER THAN THE AGE OF 50 WHO HAVE HAD A SIGMOIDOSCOPY OR COLONOSCOPY, BY YEARLY INCOME

YEARLY INCOME	NUMBER	PERCENTAGE	CI*
Less than $25,000	37,906	61.2%	(56.6 – 65.7)
$25,000 – $34,999	20,393	67.2%	(59.6 – 74.8)
$35,000 – $49,999	30,696	71.3%	(65.6 – 77.0)
$50,000 – $74,999	36,807	72.5%	(66.8 – 78.1)
$75,000 or more	36,133	71.6%	(66.8 – 76.4)

*CI stands for Confidence Interval
Source: 2007 Rhode Island Behavioral Risk Factor Surveillance System



INCREASE THE PROPORTION OF ELIGIBLE RHODE ISLAND ADULTS WHO ARE SCREENED WITH COLONOSCOPY— REGARDLESS OF HEALTHCARE COVERAGE OR ABILITY TO PAY.

WORKGROUP

TREATMENT

CHAIR: MICHAEL P. VEZERIDIS, MD, CO-CHAIRS: KRISTINE DIANA, BRIAN DENTON

The overarching goal of the Treatment Workgroup is to increase Rhode Island residents' awareness, access, and participation in cancer clinical trials. Cancer mortality could decline significantly with increased participation in approved clinical trials.

The workgroup aims to address barriers to participation including: lack of understanding and knowledge of the research and enrollment process, lack of diversity in recruiting efforts, and organizational impediments such as the inability for low-income people to miss work for clinical trial appointments. To date, the workgroup has assessed current clinical trial enrollment practices and has delivered clinical trial trainings to key health professional organizations, patient groups, and community-based organizations.

CANCER MORTALITY COULD DECLINE SIGNIFICANTLY WITH INCREASED PARTICIPATION IN APPROVED CLINICAL TRIALS.

The workgroup strives to increase participation in clinical trials among low-income people, seniors, and racial and ethnic minorities by ensuring all cancer treatment providers are in compliance with standards for culturally- and linguistically-appropriate services.

WORKGROUP

SURVIVORSHIP

CHAIR: LINDA DZIOBEK, CO-CHAIR: JAMES WILLSEY

The goal of the Survivorship Workgroup is to promote the well being and quality of life of Rhode Islanders who are living with, through, and beyond cancer. Currently, the workgroup is focused on promoting existing cancer survivor resources and identifying additional survivor needs.

> PROMOTE THE WELL BEING AND QUALITY OF LIFE OF RHODE ISLANDERS WHO ARE LIVING WITH, THROUGH, AND BEYOND CANCER.

To promote the currently existing resources for survivors, the workgroup communicates with the statewide information and referral helpline staff to ensure staff have up-to-date information on all the resources available in the state. In addition, the workgroup aims to educate the community regarding available resources.

To identify additional needs, the workgroup has developed a Cancer Survivorship Assessment Survey that targets cancer survivors, providers, and cancer organizations. The areas of focus are: survivor socio-demographic characteristics and insurance coverage; diagnosis and treatment; physical and mental health; psychosocial characteristics; family needs at different cancer stages; and recommendations for improving cancer treatment and support for patients and their families. The workgroup is also specifically looking at access to resources by underserved populations.

WORKGROUP

PALLIATIVE CARE

CHAIR: RUTH MARANDA

The goal of the Palliative Care Workgroup is to improve access to palliative care to prevent and relieve suffering and support the best possible quality of life for patients and their families. The focus of the workgroup in 2008 was to assess the use of hospice and palliative care in the state.

A STATEWIDE REVIEW SHOWED HOSPICE AND PALLIATIVE CARE WERE CONSIDERED UNDERUTILIZED IN RHODE ISLAND.

In 2007, a statewide review showed hospice and palliative care were considered underutilized in Rhode Island. Only one of the 16 hospitals in the state had a formal palliative care program, leaving the majority of hospitalized patients without access to palliative care services.

The workgroup is in the formative stages of updating this assessment and will develop an education and action plan, specifically addressing the need for any policy change. In addition, with several key Partnership members participating on the Rhode Island Attorney General's End of Life Task Force, the workgroup will seek to collaborate with this task force to improve services for people with cancer who are in need of end-of-life care.

WORKGROUP

SURVEILLANCE & EVALUATION

CHAIR: JOHN P. FULTON, PhD, CO-CHAIR: DAVID ROUSSEAU, CONSULTANT: ALVARO TINAJERO, MD, MPH, ScM

The goal of the Surveillance and Evaluation Workgroup is to ensure each of the six workgroups' recommendations for activities and policy change are researched thoroughly and based on scientific evidence. They assist other workgroups with conducting literature reviews, developing and implementing surveys and other data collection tools, and analyzing data. As each workgroup works towards the implementation of their priorities within the state plan, this workgroup helps them make sure that all objectives are measurable, sets baselines and targets for objectives, and evaluates progress towards those end points. In aggregate, this workgroup evaluates the implementation of the *Rhode Island Comprehensive Cancer Control State Plan*, evaluating successes in all areas. The workgroup also utilizes the Rhode Island Cancer Registry to actively monitor the trends in cancer incidence, mortality, and disparities in Rhode Island.

THE PARTNERSHIP MOMENTUM

MEMBERSHIP: DIVERSE AND GROWING

Through strong recruitment efforts in 2008, Partnership membership grew to more than 100 members, including many community members and individuals. To reflect this membership diversity, The Partnership updated its by-laws to include individuals as members, rather than solely organizations. To assist the growing Partnership, The Partnership hired both a coalition manager and a program evaluator and added a treasurer to the Board of Directors. The Partnership will be assessing member satisfaction annually and include this assessment as part of the framework for ongoing evaluation. The Partnership is committed to continuing its efforts to grow and diversify, striving to be an effective agent of change.

THE SUMMITS: BRINGING PEOPLE TOGETHER

The purpose of the annual summit is to bring together Partnership members, community members, and organizations with an interest in cancer. Each summit has speakers and workshops that highlight the work of The Partnership and focus on specific Partnership priorities. Topics vary from year to year.

2008 Rhode Island Cancer Summit:
Navigating Cancer Care

Keynote Speakers:

» Dr. Kenneth Miller, Assistant Professor of Medicine at Yale University and director of several oncology programs at the Yale Cancer Center and Yale-New Haven Hospital.

» Richard Boyajian, a cancer survivor and nurse practitioner, affiliated with the Lance Armstrong Foundation Adult Survivorship Clinic and the Perini Family Survivors' Center at Dana Farber Cancer Institute.

2009 Rhode Island Cancer Summit:
The Burden of Cancer in Rhode Island: Partnering to Win

Keynote Speaker:

» Dr. Otis Brawley, Chief Medical and Scientific Officer & Executive Vice President for Research and Cancer Control Science at the American Cancer Society, an internist and oncologist in Atlanta, and a professor at Emory University in both the Medical School and School of Public Health.

THE PARTNERSHIP TO REDUCE CANCER IN RHODE ISLAND IS CONSTANTLY MAKING STRIDES TO STRENGTHEN OUR ORGANIZATION AND POSITION OURSELVES TO BETTER IMPACT CANCER CONTROL IN RHODE ISLAND.

WORKGROUPS: INSTRUMENTS OF CHANGE

In 2008, workgroups have:

- Utilized the Rhode Island Department of Health KIDSNET database to ensure that adolescents complete all three doses of the HPV vaccination series.
- Worked with local gastroenterologists and hospitals to create a screening program that will provide free colonoscopies to people who cannot afford them.
- Developed and are currently implementing surveys to collect data on populations where there is limited information, such as clinical trial participants and cancer survivors.
- Visited numerous senior centers around the state to speak about the importance of colorectal cancer screening for anyone, age 50 or older.

Currently, workgroups are developing Action Plans for the 2009–2010 year. These plans will serve as guides, mapping out the necessary steps to reach each workgroup's goals and objectives. In addition, a formal evaluation plan will be developed to measure progress towards these goals and objectives.

COMMUNICATIONS AND PUBLIC RELATIONS: SPREADING THE MESSAGE

The Partnership has been working to increase statewide communication. Its website is currently being updated and enhanced to become a tool to disseminate information and market The Partnership. The new website will be interactive and will host the most up-to-date Partnership information and activities. The workgroups are developing web-based information sharing sites to serve as easily accessible places to post announcements, store meeting minutes for quick reference, and post and edit collaborative documents.

The Partnership to Reduce Cancer in Rhode Island

RHODE ISLAND DEPARTMENT OF HEALTH

www.cancercoalition.ri.gov
www.health.ri.gov